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Review

Affordability of cancer care in the United Kingdom – Is it time to introduce user charges?

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ABSTRACT

Context: In high income countries the costs of delivering high quality equitable care are outstripping present budgets. This article reviews the affordability of cancer care in these countries with particular reference to the United Kingdom (U.K.). The question remains as to whether patients should contribute to their cancer treatment through the introduction of user charges, and whether such payments can be assimilated without undermining efficiency and equity of health care access.

Methods: In our review we analyse the drivers of increased cancer care utilisation, the current policies designed to control rising costs, and the potential impact of introducing patient user charges. The article also explores whether our understanding of behavioural economics could be used to create “nudge” policies that drive rational health care consumption.

Findings: The costs of cancer care in the U.K. are increasing at an unprecedented rate, driven by demographic changes, innovation (radiotherapy, drugs and imaging) and consumerism within health care. Budgets are tightly constrained and health technology assessments designed to ensure coverage of high value interventions have come under significant public and political scrutiny. User charges potentially provide a framework to “nudge” patients from low value care of limited effectiveness towards high value cost effective treatment, thereby increasing overall efficiency. However supply side controls are equally relevant with greater focus on physician test ordering, and improving the quality of doctor–patient communication, especially when discussing treatment options towards the end of life.

Conclusions: Fiscal sustainability of health care financing remains a key public policy concern. Attempts at ensuring coverage of cost effective treatments have been continuously challenged and without new policies, sustainability trade-offs may be necessary with potential rationing of high value treatments. User charges provide a potential means of sustaining spending proportional to the projected rise in number of cancer cases, whilst embracing technological innovations which could potentially improve outcomes.

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Introduction

In the last fiscal (2011/12) year the United Kingdom's (U.K.) Department of Health budget stood at £106.66 billion, an increase compared to 2010/11 (£105.45 billion), although in real terms this was a budget cut of 1.2%. Additional pressure on NHS (National Health Service) budgets has been placed by the "Nicholson challenge" which is seeking efficiency savings of more than £20 billion by 2015 in order to meet projected patient demand [1]. Of total NHS spend, cancer care accounted for £5.81 billion, equating to 5.6% of total NHS budget [2]. In comparison France and Sweden spend approximately 10% and 7%, respectively, of their total healthcare spend on cancer care [3]. Political prioritisation of cancer in the U.K. has been matched with a 75% increase in cancer care spending between 2003/04 and 2009/10 (although funding for cancer was reduced comparatively in 2010/11). Indeed only social care and diabetes have received a greater percentage increase in funding over this time period. As it stands then the cancer community in the U.K. should be in a good position. Major public policy changes, including a National Cancer Plan have been coupled to real spending increases.

However, there is a real concern regarding the rising costs of delivering high quality cancer care in the U.K. as well as many other high income countries. In high income countries the public policy consensus is that costs of delivering high quality equitable care are outstripping the national budgets [4]. In the U.S.A., the total spending on cancer care has grown from \$27 billion in 1990 to \$124 billion in 2010, with a further projected rise in spending to \$157 billion, taking into account inflation, by 2020 [5,6]. Given the fiscal constraints in the NHS, the affordability of cancer care over the next two decades needs to be urgently addressed given that increases in the costs of cancer care are likely to supersede overall health care inflation [4]. This is being driven by a number of factors; technological innovation, rising costs of hospital care, and an increase in the proportion of individuals susceptible to malignancy as a result of demographic transitions; essentially a rapidly ageing population [7]. Within the U.K. there is currently an ongoing public and political debate regarding the escalating costs of cancer treatment and how best this should be funded [8,9].

A particularly sensitive public policy issue is whether patients should contribute to their cancer treatment, through the introduction of user charges or copayments. Ultimately the aim would be to sustain spending proportional to the projected rise in number of cancer cases, whilst embracing technological innovations which could potentially improve disease outcomes. This discussion is important, as all stakeholders would want to avoid alternative sustainability trade-offs that may result in the rationing of high value and cost effective care.

In our analysis of the U.K.'s public policy regarding affordable cancer care we examine the drivers of increased cancer care utilisation and costs in the U.K., the policies designed to control rising costs, and the impact that the introduction of patient user charges could have on cancer care. The debate can be widened to encompass other high income countries within Europe which are experiencing very similar demographic transitions. Whether operating a tax based or social health insurance system of health care financing, these countries are under increasing pressure to achieve fiscal sustainability, and despite user charges being utilised more readily across Europe, cancer care is frequently

excluded from such charges. However in reality can we afford to do so?

The demographic transition

Stuart Jay Olshansky has described our modern era as the "age of delayed chronic diseases" with declines in mortality at older ages responsible for increases in life expectancy and population growth [7]. As a result the U.K. population size is expected to increase from 62 million to 71 million by 2030, with the proportion of individuals aged over 65 set to rise from its current level of 17–25% by 2030 (Eurostat 2013). Horiuchi has postulated that we are approaching the "high technology" era where cancer, will become the dominant cause of mortality in the developed world [10]. In the U.S., cancer is now the leading cause of death in those under 85 years, a pattern which is emerging in the U.K., where at present circulatory diseases remain the predominant cause of mortality but which are on a downward trajectory with cancer soon to take the top spot [11].

In 1975 the projected lifetime cancer risk for men in the U.K. was 25% but this figure has risen to an estimated 45% in 2012 [12]. Whilst the age standardised incidence for all cancers combined is expected to decrease by 1% leading up to 2030, the prevalence is projected to increase as a result of the demographic transition. The number of cancers in men is expected to increase by 55%, from 149,169 to 231,026 between 2007 and 2030, and by 35% from 148,716 to 200,929 for women. Prostate, breast, lung and colorectal cancer are predicted to continue to be the commonest tumour types, however increases are expected for rarer sites such as melanoma, non-Hodgkin's lymphoma and oropharyngeal cancer [13,14]. Furthermore the burden of malignancy disproportionately affects older persons, with 69% of cancers in men and 62% in women diagnosed in those aged over 65 in 2011 [14].

Innovation

There have been significant technological developments in cancer care which have sought to facilitate earlier diagnosis, aid treatment selection and improve disease control and survival outcomes. However, recent innovations in imaging, radiation therapy and drug development have come at a considerable cost to already stretched health care budgets [4].

Imaging

Between 1996 and 2006 the imaging costs associated with U.K. cancer care increased from 5.1% to 10.3% of the total budget [4]. Diagnostic accuracy associated with imaging techniques such as computerised tomography (CT) and magnetic resonance imaging (MRI) has improved. However, it is the introduction of hybrid scanners such as positron emission tomography with CT imaging (PET-CT) that have increased the sophistication of treatment selection [15]. These technologies combine anatomical and molecular imaging techniques to achieve more accurate and early diagnosis of new and recurrent disease, provide detailed staging information, and assess treatment response [16]. For example in Hodgkin's lymphoma PET-CT is used to detect biological tumour response to a therapeutic intervention, guiding subsequent treatment choice [17].

These benefits come at significant capital and operational costs and evidence based guidelines have therefore attempted to prioritise their utility in particular disease sites. However these public policy cost containment approaches always lag behind the development of increasingly sophisticated imaging modalities and their novel uses in defining treatment selection, duration, and treatment adaptation [18]. Evidence suggests that technological innovation in imaging is a major factor in the rapid inflation of cancer care costs, and this does not appear to be slowing [19].

Radiation technology

Radiotherapy is required by 60% of patients with cancer, and is directly involved in the management of 40% of those patients who are cured [20,21]. Currently radiotherapy technology expenditure absorbs about 5% of the total U.K. cancer budget [22]. Taking into account all costs across the life cycle of the resource, it is, broadly speaking more cost effective than surgery and chemotherapy with a 21 fraction course of radical radiotherapy costing 3239 euro (± 566) [23]. However, the U.K. is in a paradoxical situation where delivering affordable radiotherapy over the next twenty years is being compromised by both current under-capacity and under-investment in 'standard' radiotherapy and also over-penetration of newer radiotherapy technologies that have far greater associated costs [24].

Addressing the shortfall in radiotherapy capacity in the U.K. in 2007, the National Radiotherapy Advisory Group report (NRAG) set a series of targets based on projected radiotherapy demand and recommended a 63% increase in current capacity [25]. An interim goal of 40,000 radiotherapy attendances per million of the population (pmp) by 2010 (now considered an underestimate based on latest projections) was set. However, audit results from 2010/11 show that there were only 33,000 attendances pmp. Despite capital investment and an overall 13% increase in activity over 6 years, this was still insufficient to meet current demand. By 2016 the requirement will be 55,000 attendances pmp, requiring an extra 147 radiotherapy machines [26]. Given the current financial restrictions in place this is unlikely to be achieved as each machine typically costs £1.4 million, a cost which excludes the necessary staffing, training, software and quality assurance outlay. Furthermore the U.K. government in its 2010 spending review recommended a 17% reduction in capital investment from 5.1 billion in 2010–2011 to 4.6 billion in 2014–2015 [27].

The U.K. is also lagging behind in well-established second generation radiotherapy technologies. Advances in radiotherapy technology aim to enhance the *therapeutic ratio* by improving the precision of radiation delivery to the target area. This allows dose escalation to the primary tumour with the aim of better local tumour control whilst achieving a concomitant reduction in radiation dose to normal tissues, reducing the risk of acute and long term morbidity. Intensity modulated radiotherapy (IMRT) modulates the treatment beam to achieve highly conformal radiation dose distributions and steep dose gradients compared to standard 3D conformal radiotherapy [28]. It is recommended in the treatment of a number of disease sites including head and neck cancers. However, in the U.K. demand is not being met at present with the most recent audit demonstrating that only 25% of the recommended number of IMRT treatments are being delivered nationally [26].

Whilst the U.K. lags behind in delivering affordable standard radiotherapy technologies it is also seeing an influx of new radiation technologies at an unprecedented rate. Next generation IMRT has been further refined to enable radiation beam shaping while the beam is moving in a circle around the target. Commercially these machines go under the name of RapidArc® or VMAT® when using a standard linear accelerator or as Tomotherapy®

when using a dedicated linear accelerator only treating with arcs.

Stereotactic body radiotherapy (SBRT) represents a further advance and refers to the "precise irradiation of an image-defined extra-cranial lesion using a high radiation dose in a small number of fractions." This technique requires complex methods of immobilisation and target localisation and as a result is more resource intensive than conventional 3D conformal radiotherapy in terms of equipment and planning [29,30]. It is not known whether SBRT offers superior outcomes in terms of long term local control and quality of life for all potential indications [31,32]. It does, though, come with a significant increase in price both in capital and revenue terms. Recent estimates value a new cyberknife machine at approximately £2.5 million compared to £1.4 million for a new linear accelerator. These figures do not take into account the additional software, personnel costs and quality assurance associated with SBRT [33].

Proton beam therapy has also been making inroads into the NHS. It is the treatment modality of choice for specified adult (e.g. skull base chordoma), and paediatric tumours (e.g. cranio-pharyngioma, rhabdomyosarcoma). Principally it aims to reduce morbidity from side effects and increase cure rates, which could not be achieved with conventional RT techniques without undue toxicity [34]. However the majority of the evidence is based on theoretical models and small selected case series due to the difficulties in conducting large randomised control trials for radiation technologies [24,35].

There are plans to put in place two proton beam radiation therapy units, the first of which is likely to be operational by 2017. The expected total cost is in the region of £250 million (equipment alone costs £60–80 million) with a capacity to treat 1100 patients a year at both sites at a total cost of £37 million per annum. Currently the NHS commissioning group is projected to spend £30 million in 2014–15 to send 400 patients abroad for treatment [36].

The requirement to embrace new radiation technologies yet build on current capacity levels to meet unmet need places considerable strain on the financial resources available. Unless efficiency gains are achieved the NHS will not be able to sustain and increase the necessary provision of radiotherapy let alone integrate technological advances which could improve outcomes further. Of all the new technologies, the case of radiotherapy demonstrates the paradox of public policy towards affordable cancer care. A failure to deliver basic service needs, yet willingness to 'over-spend' on technologies which have not been demonstrated to be cost effective. How much of this is fuelled by the desire to compete with other cancer centres since the advent of patient choice [37] in order to attract new patients and increase their market share remains as yet unknown.

Cancer drugs

Cancer drugs represent a rising proportion of the cancer care budget [38]. Between 2000 and 2009, 23 new drugs were brought to market for use in cancer patients. Targeted drugs such as tyrosine kinase inhibitors and monoclonal antibodies dominate the portfolio of cancer drugs entering the market (only one cytotoxic agent was launched between 2005 and 2009) [39]. These drugs target sub-populations that possess specific genetic or proteomic alterations which are implicated in cancer pathogenesis. The costs associated with these "blockbuster" drugs are increasing dramatically. The cost of an average course of non-hormonal systemic therapy in the U.K. has increased from 34% of per capita GDP between 1995 and 1999 to 67% per capita GDP in 2005–2009 [39].

However, it should not be forgotten that molecular targeted agents such as imatinib [40], rituximab [41] and trastuzumab [42]

have either improved cure rates or extended survival in certain tumours where previous therapeutic options were limited. Additionally, pharmaceutical companies do face significant research and development costs when bringing an anticancer agent to market for increasingly limited populations, although it is highly doubtful whether the costs of new drug development are as high as claimed (in the region of 1–2 billion US dollars) [43,44]. More sober and dispassionate calculations suggest a half or even a third of this [45].

Rising administrative costs and bureaucracy of trial procedure have also discouraged academic (investigator initiated) clinical research, resulting in most trials being conducted by for-profit pharmaceutical companies [46]. This has resulted in the launch of several high priced drugs of questionable efficacy to recoup such inflated trial costs [47]. However, in many cases the higher prices set for new cancer medicines were not accompanied by proportional improvements in health [48]. In the U.S. total health expenditures for cancer care increased 9% from 2001 to 2004, despite the composite indicator for quality of cancer care during this period only increasing by 3.6% [49].

The role of health technology assessments

Attempts to control the provision of drugs not deemed cost effective by health technology assessment (HTA) agencies such as the U.K.'s National Institute for Health and Care Excellence (NICE) have been met with widespread public and professional discontent [50,51]. NICE was designed to ensure that all patients received the most effective treatment (by eliminating postcode prescribing), basing their value judgements on a thorough period of consultation and health economic impact modelling [52]. They provide valuable in-depth analysis of new drugs and technologies focusing on both short and long term outcomes of treatment and direct patient benefits. They also highlight flaws in trial design and misrepresentation of positive results. For example, erlotinib when administered to pancreatic cancer patients demonstrated a median survival benefit of 0.33 months when combined with gemcitabine, the current standard treatment, with increased risk of toxicities [53]. There was an incremental cost per QALY of over a \$100,000. Based on this evidence this drug was not approved by NICE although it had received marketing approval by the US Food and Drug Administration (FDA) and European Medicines Agency (EMA).

A value threshold of £30,000 per QALY gained was set by NICE when making coverage decisions for treatments. The advantage of the cost per QALY was its universality when making decisions regarding the whole spectrum of health care interventions across all specialities. However, denial of treatment on the basis of an abstract notion of life's value does not come without its ethical dilemmas.

These difficulties are exacerbated when the same drugs that have been refused in the U.K. are widely available in the U.S. and Europe. Between 2004 and 2008, 46 anticancer drugs were granted a European license following FDA approval. NICE made recommendations for 18 (39%) of these drugs to be freely available on the NHS with 11 (24%) still awaiting approval. In contrast all of these drugs were covered by the three main insurance providers in the U.S. [54,55].

However a comparison of coverage policies for expensive cancer drugs between the U.K. and U.S. demonstrates that despite these findings, inequities in access may be particularly acute in the U.S. Currently all expensive cancer drugs undergo a rigorous health technology assessment in the U.K. prior to determining universal coverage. However, in the U.S. access may be entirely contingent on an individual's health insurance coverage policy and ability to pay with few patients having free access to expensive cancer drugs when needed. This creates inequities and exacerbates the risk of

financial hardship or prevents patients receiving these drugs all together [56]. This lack of transparency and consistency, calls into question the fairness of coverage and cost sharing decisions in the U.S. despite the rhetoric suggesting that in fact access to high cost drugs is easier than in the U.K [57].

Public disapproval of NICE decisions has caused considerable political consternation. There have been a series of legal challenges resulting in the approval of both trastuzumab and imatinib which were both above the £30,000 QALY threshold [58]. Following approval of sunitinib, NICE reviewed its policy for end of life drugs, specifically the value placed on gains in survival and quality of life for incurable conditions where there remains a paucity of reasonable alternatives [59]. Other drugs have since been approved, for example vemurafenib which has been authorised for patients with BRAF V600 mutation positive malignant melanoma and is estimated to cost £1750 per week prior to any discounting [60]. A recent review estimated that between 2009 and 2011 the additional cost to the NHS of providing new interventions under the end of life criteria was 549 million pounds per annum [61].

The government has attempted to improve access further by initiating the Cancer Drugs Fund. This is a £200 million ring fenced fund that was set up to provide access to cancer drugs that were not deemed cost effective by NICE. This will officially finish in January 2014 [62]. However, critics have argued that such a fund, which is administered by oncologists, creates an inconsistent and unfair model of resource allocation and that the fund represents a diversion from the fair allocation of NHS resources for maximum societal benefit [63].

Value based pricing (VBP) is expected to come into effect in January 2014 in which NICE will no longer make explicit decisions regarding funding but instead provide HTAs for new drugs. VBP represents society's maximal willingness to pay for an intervention through a public healthcare system following a rigorous assessment of the cost effectiveness of other products. It aims to maintain equity with the payer driving utilisation through evidence based guidelines [64]. Drugs should be innovative, meet unmet needs, and demonstrate tangible clinical benefits. All laudable aims but as it stands VBP in the U.K. lacks any form of comparative or quantitative framing for the purposes of developing rigorous public policy.

In a recent survey of societal preferences for NHS funding, respondents agreed with the premise of value based pricing, but the majority did not believe that extra value should be placed for specific groups such as children, cancer patients or those with reduced life expectancy [65]. A further study also found that the majority of cancer patients and the general public did not believe that the NHS should fund drugs that have not been approved by NICE [66].

UK public policy and the tax payer

The U.K. provides a uniform package of health benefits irrespective of income. However, the most cursory examination of the cost trajectory of cancer health technologies means that new approaches to paying for cancer care need to be found. The NHS has attempted to ration interventions through supply side controls, providing those that are deemed most cost effective following independent evaluation. As it stands it appears that such trade-offs are still politically unpalatable. Cancer is too personal and emotive for the public to accept decisions on rationing. Furthermore the numbers of cancer cases are expected to increase, with no concomitant rise in the budget expected.

One option would be to raise general taxation. However, recent increases in taxation for the highest earners have been gained little political traction [67]. Furthermore any increase in taxation will have a number of competing calls on these funds (e.g. education or transport) and there is no guarantee that increased tax revenue

will ultimately lead to higher health expenditure, particularly on cancer care.

Despite being a radical departure from current public policy discourse on affordable cancer care, user charges, already the subject of widespread debate [68,69], could provide the key to long term sustainability of high quality cancer care in the U.K. A copayment is a fee levied either in the form of a (1) *deductible* (a fixed amount to be paid by patients in a given time period towards health care, above which is reimbursed by the third party payer), (2) *proportional copayment* (a percentage of the total cost of the service/product) or (3) *fixed copayment* (flat rate fee e.g. pharmaceutical prescription charge).

User charges – the debate

During the 1960s and 70s there was considerable backlash towards medical paternalism across the UK and most high-income countries. The shift to individuals to take responsibility for their health needs and decision making marked, so it was assumed, a new responsibility for health, rooted in the individual [70].

However, there is evidence that patients are reluctant to take responsibility for their health care needs [71]. Missed appointments or non-adherence with drugs represent a form of non-compliance and whilst several factors may mitigate, it could conceivably point to a lack of ownership of the issue [72]. This in part has been facilitated by universal health care coverage in the U.K., whereby patients are shielded from direct health care costs at the point of access. There is no incentive to restrain consumption, leading to potential overuse as consumers can use health care for as long as there is perceived benefit no matter how marginal or at what cost [73], essentially a form of moral hazard in healthcare systems. This is not something that applies to patients alone but also to health professionals, who within budgetary and fee for service payment schemes may not have the necessary incentives to achieve efficiency gains and moderate resource utilisation [74].

Advocates of user charges believe it empowers patients to take greater responsibility for their health, encouraging greater focus on quality and cost of health care services [75,76]. Out of pocket payments are routine in the U.S., with individuals having to pay part of the cost for a physician visit, hospitalisation or other service e.g. chemotherapy [77]. This is applicable to both Medicare and privately insured individuals, with payers and insurers increasing their cost sharing requirements [78].

In Europe copayments are also used in a variety of forms [79]. In France there is an escalating scale of proportional copayments (35%, 70% or 80%) depending on the medical benefit of the drug and seriousness of the condition [80]. In the Netherlands patients pay a deductible copayment for the first 220 Euros of their health care costs, after which all care is covered by the third party payer [76]. In the U.K. we have already adopted copayments for dental and optician services, as well as routine prescriptions, for which a fixed charge (£7.85) is applied. Currently prescription charges generate approximately 1% of the NHS budget in income [81]. Could we therefore reasonably integrate a series of copayments for all health care services? This would include routine clinic appointments, diagnostic and treatment interventions, and inpatient stays. Naturally any system would require exemptions to ensure that low income groups and the most vulnerable (e.g. children, older people, those with certain medical conditions) are not disproportionately affected. Cancer patients, for example, receiving treatment directly related to their cancer or for conditions resulting from previous treatment have been exempt from prescription charges since 2009 in the U.K. [82].

However, there remain numerous objections to user charges on the grounds of inequity and inefficiency. Goldman et al. in a

review of copayments in the U.S. found that charging patients for health care costs resulted in lower rates of compliance, and more frequent discontinuation of treatment [83,84]. This has been demonstrated for cancer screening uptake [77] and adherence to aromatase inhibitors for breast cancer, especially amongst elderly patients [85]. However the impact on health outcomes (quality of life, survival) remains inconclusive.

The RAND health insurance experiment conducted in the 1970s and 1980s reviewed the impact of an escalating system of copayments in the USA on health care utilisation. The study found that individuals across all income groups who faced a user charge reduced their health care usage, but there was no discrimination for high value (effective) or low value care (inappropriate or treatments of marginal benefit) [86].

Furthermore, the higher the level of cost sharing the greater the reduction in health utilisation, with a more pronounced impact on low income groups [87]. There is also concern of a “squeezed balloon effect” whereby user charges for prescription drugs result in an increase in the use of other services e.g. emergency care. Possible causes include patients forgoing necessary treatment and presenting *in extremis* to hospital services or patients preferring to attend secondary care to avoid paying user charges [88]. One study demonstrated an increased frequency of admissions (hospital care was covered by insurance) for cancer patients required to pay higher copayments [89]. The other concern is one of fairness. Cancer patients and their families already experience significant financial costs as a result of a cancer diagnosis, regardless of socio-demographic group. Those who are employed or have financial dependents are particularly affected by the potential loss of earning and costs associated with accessing services [90].

The public policy issue is whether copayments can be introduced which do not negatively impact on low-income groups yet enhances efficiency of health care delivery and maintenance of high quality care.

User charges to raise revenue

One argument is that demand for cancer care is not price sensitive and that moral hazard is not a factor as decisions regarding diagnostic and treatment interventions are made by informed physicians rather than uninformed patients [91]. Furthermore cancer is a potentially life threatening condition and patients would be willing to receive (and potentially pay) for therapies even if they are of marginal benefit [92]. User charges in these circumstances are likely to generate revenue if applied to cancer care, as the likelihood of patients refusing a recommended course of action (particularly if low income individuals are protected with exemptions) is small. Evidence for patients’ willingness to pay for cancer treatment comes from a number of “Willingness to Pay” (WTP) studies [93,94].

These have demonstrated that cancer patients, even with metastatic cancer, would be willing to pay for therapies that provide tangible benefits in terms of disease control e.g. survival and quality of life. The amount patients are willing to pay, whilst still less than the true cost, of the drug, increases in line with superior outcomes. However, there were socio-demographic differences, with elderly, and unemployed patients less willing to pay, compared to patients who had higher incomes, and higher levels of educational attainment [95]. Few WTP studies have been performed in cancer care, and this is potentially an avenue for future research particularly with the advent of value based pricing. However, by choosing those areas of medicine that are valued highly by patients (e.g. cancer care, kidney disease, rheumatoid arthritis) there may be greater acceptance of user charges compared to those interventions that do not provide improvements in length or

quality of life. However it goes without saying that the reverse scenario may be preferred by patients, with a preference for charges to be applied to none life saving care and exemptions from any costs associated with life threatening illness, as practised in the French healthcare system [80].

User charges – to encourage rational health care consumption

When reviewing patient demand for cancer interventions it is important to realise that it is not necessarily driven by rational reasoning on the basis of available evidence. Our understanding of behavioural economics has highlighted how our decision making processes are prone to biases which may cause “reasoning failure” [96]. Patients are often required to weigh up risks of survival, toxicity and quality of life when making treatment decisions. They may struggle with probabilities, over-estimating their level of risk of disease and the potential benefits of treatment [97], resulting in choices that negatively impact on welfare [98]. Under these circumstances patients may also be influenced by an array of emotions, for example fear and grief [99].

Studies of cancer patients have found that demands for particular treatments do not come from a neutral evaluation of risks and benefits but rather from a perception of hope even when faced with, a high likelihood of major toxicity and low benefit [100]. This is particularly relevant when cancer patients assess end of life treatments, where they have been shown to value hope and are willing to gamble on an intervention [95]. Such findings are entirely in line with prospect theory where decisions made under conditions of gains and losses are very different, and not subject to a state of maximising personal utility [101].

Moral hazard may also play an additional role in defining the patient’s perceived losses and gains associated with treatment. If a patient is shielded from the costs of health care, they may be more amenable to accessing health care of marginal benefit. The question then is how these insights can be utilised to frame the user charges policy?

Libertarian Paternalism (LP) may be one such approach. LP aims to provide a framework where individuals make decisions which benefit themselves and society, whilst still maintaining a range of available options [102]. In other words by changing the “choice architecture” for decision making individuals can be “nudged” into making the right choices [103]. Can user charges therefore be used to nudge patients into making decision that optimise health care efficiency?

A system of value based user charges could redirect (“nudge”) individuals from low value to more cost effective treatment options. In France, for example, patients wishing to seek direct specialist access rather than obtain referral from their general practitioner are required to pay higher charges for each consultation (50% proportional copayment rather than 30%) [104]. A similar initiative could be considered for patients wishing to have therapeutic agents considered to be of low value, particularly those treatments considered in the last weeks of life. A substantial proportion of the total cost of cancer care is delivered in the last few weeks or days of life with much of this care lacking evidence and achieving limited benefit in terms of survival or symptom control [105]. We know that in this situation patients may not make rational decisions, and copayments could redirect care to more cost effective options such as best supportive care. It also provides an opportunity for patients to obtain information about treatment options and become empowered in the decision making process.

A similar strategy may be considered for new radiation technologies where insufficient data may be available to justify coverage over and above standard conformal 3D therapy. The

NHS in this circumstance would reimburse the costs of standard evidence based therapy with patients paying additional costs of alternative technologies if they so wish. There is evidence to support this approach. One study demonstrated that user charges made patients more discerning and more likely to reconsider utilisation of controversial services e.g. prostate cancer screening as opposed to proven and recommended interventions such as breast cancer screening [106].

There are two main caveats with this approach in framing public policy. Firstly there is often considerable uncertainty regarding the effectiveness of interventions. This is especially relevant for radiation technologies where the pace of software and hardware advances make performing RCTs difficult [24]. Secondly the clinical and cost effectiveness of an intervention can vary depending on individual patient characteristics and therefore setting a system of charges in view of this heterogeneity may undermine efficiency and fairness [88].

Drummond et al. [91], considered the use of optional copayments in a value based pricing (VBP) system. Copayments would provide an opportunity for individuals to purchase care that was not deemed to deliver enough social value for the cost. VBP would also aim to provide accurate information on the costs and effectiveness of alternative treatment strategies set above the VBP cost. This would allow patients to make more informed decisions regarding their treatment choices but would still not restrict access to drugs that society is willing to pay for.

A similar strategy has been outlined by Garratini et al. [76], who proposed a reference based pricing arrangement, similar to those adopted in countries such as Germany and the Netherlands. Here groups of therapeutically equivalent drugs (both generic and branded) are priced according to the lowest-priced drug in the cluster or an average price for the whole cluster. Copayments are required by patients for those drugs which are set at a price above the listed reference price (RP). This has the effect of encouraging pharmaceutical companies to drive down the cost of their drugs in order to maintain market share [107].

In the case of cancer drugs, a “life gain threshold” is set for a given cancer according to currently available therapies e.g. 6 months for colorectal cancer [108]. New therapies are then compared with standard therapies to determine the added benefit in terms of life gain. Drugs not considered to produce adequate life gain would not be reimbursed and instead a charge would be applied to the standard therapy price to create an “automatic reference price.” The effect would be to restrict expenditure of third party payers on drugs (or radiation technologies), particularly at the end of life that provide marginal benefit in terms of survival or quality of life, but patients would still have access to these treatments.

In addition, raising the life gain threshold for reimbursement would encourage pharmaceutical companies to focus on producing innovative drugs that provide significant clinical outcomes, whilst discouraging companies from setting high prices above the agreed reference price. The cancer drugs fund in many respects has, amongst many other structural problems, disincentivised pharmaceutical companies from reducing their prices or from releasing drugs with only marginal benefits.

However these systems are open to “gaming.” For example the government could set the societal willingness to pay threshold at a level, which would encourage copayments from the majority, off-setting the costs to the NHS [91]. However this could result in low income groups not accessing care. Likewise pharmaceutical companies may set prices for an effective drug well above the VBP, to encourage copayments resulting once again in access issues to the most vulnerable and deprived communities.

A further argument points to the absence of restrictions for those drugs not considered to be of sufficient value to be reimbursed, but remain freely available for those who can afford it. As a result this

could result in perceived inequity not necessarily in outcomes, but in superior access on the basis of an ability to pay. This is a key concern with the current top-up system for cancer drugs in the U.K. [109].

Information provision as a means of encouraging rational health care consumption

A perceived benefit of implementing a user charges policy is the concomitant information that is provided to patients regarding the value of the treatment they are consuming. This could improve health service efficiency both in terms of clinical outcomes and financial costs by reducing utilisation of low value care [110]. However, can we create a “nudge” public policy in cancer that reduces information asymmetry and empowers patients to take responsibility for their health, without introducing explicit charges?

As an example a patient due to receive a course of radiotherapy could be sent a letter prior to attendance detailing the total cost of delivering the treatment (e.g. staff time, clinic space, cost per fraction of radiotherapy). There would be particular reference to the fact that non-attendance would result in a loss of this sum to the NHS. The patient would also be informed of current waiting times for services and that missed appointments place strain on resources and could impact on their health and that of other patients. Another option would be to provide an invoice itemising the health care services utilised by the individual with the added comment that this had been paid by the NHS.

The inclusion of pricing information aims to provide insight into the healthcare process and the costs (social and economic) associated with this, which studies have shown are undervalued by patients [111]. It therefore acts to reset the so-called *norms* by providing a frame of reference for actual health care costs. This in effect would reposition the perceived value of health care with the aim of reinforcing positive health behaviours i.e. “nudge” patients to consume healthcare more rationally [112,113]. These behavioural techniques have been used to influence physicians' test ordering behaviour. For example, there was a 31.1% cost reduction when providers were given information about the price of tests compared to the controls who were not [114].

It could have a wider impact on other areas of health utilisation (adherence, consumption of low value care, unnecessary hospital attendances). As framed by self determination theory the maintenance of choice and absence of coercive regulation strategies would encourage sustainable positive health behaviours [115]. By avoiding explicit charges this strategy is likely to be widely accepted and could facilitate future implementation of user charges if individuals are aware of the actual costs of their treatment [116]. However, it is not certain whether individuals are motivated to act in the interest of social welfare (so called knights [117]) when faced with the prospect of a shortened life expectancy.

An important argument that also needs to be considered against moral hazard is that decisions about appropriate treatment are made by informed doctors rather than patients [91]. One solution could be to focus on physician behaviour. Overutilisation of diagnostic investigations, therapeutic agents or even the frequency of follow up can all result in escalating cancer care costs. This can occur as a result of a poor knowledge on the evidence for interventions, time pressures in the clinical setting, fear of withdrawing hope or even medicolegal concerns [118]. Oncologists need to be informed and subsequently inform their patients of the real value of cancer care as this is likely to directly affect health care consumption [8]. However, this will require adequate physician training to ensure appropriate choices are made that benefit the patient and society [119]. Patients have expressed a desire to be informed of

such decisions and their rationale. Good communication in these circumstances is essential [120].

Conclusion

The public policy debate around co-payments as part of an overall strategy to deliver affordable cancer care system is finely balanced. The fact remains that the costs of cancer care in the U.K. are increasing at an unprecedented rate, driven by demographic changes, innovation and consumerism within health care. Budgets are tightly constrained and health technology assessments designed to ensure that the NHS cover those interventions that are of high value have come under significant public and political scrutiny. Evidence based medicine requires us to make explicit and judicious decisions on the care that we provide and not just offer therapy as a means of providing hope to individuals. We also need to balance the whole of society's health care needs to ensure that we use limited resources efficiently yet provide high quality evidence based care. Could the introduction of user charges in cancer care provide a means of sustaining the provision of high value services in the future whilst overcoming issues of fairness and equity in access for those in need?

Conflict of interest

The authors confirm that there are no conflicts of interest.

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